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Hanford Openness Workshop
Workshop 4
Meeting Summary
May 18, 1998

Presentation by Helen McGough, University of Washington (UW), Human Subjects Division on Privacy and Confidentiality Issues

Helen McGough explained to workshop participants that confidentiality issues become important when providing access to information. She said that it is surprising how much private information is not really private and is relatively easy to put together a lot of information about someone from the large variety of sources available. There are many risks from people knowing your private information, including loss of employment, housing, insurance, travel restrictions, loans, etc.

She gave an example of a Barrow, AK study that found a high percentage of alcoholism in the community. After the information was released the credit rating of the area plummeted. When private information is released, not only are their community-wide risks, but personal risks, including a feeling of violation, as well as learning unwanted information about others.

The Privacy Act of 1974 does offer some protection. For example, Social Security numbers are very valuable to people who want to track you, but they are private; there are very few instances when you are legally required to give them out. Norma Jean Germond brought up the point that in Oregon, student loan forms often ask for Social Security numbers.

Helen McGough agreed and explained that the Washington state drivers license system does not currently require Social Security numbers but this is being reconsidered. Researchers can ask for Social Security numbers in the course of their studies, but need to inform subjects of their rights.

She went on to explain that there are differences between "confidentiality" and "anonymity." Anonymity means there is no way to link data to identity. Confidentiality means that you can link that information, but the information is not readily available, and protections are in place to make sure that the information isn't linked.

Anonymity is much harder to accomplish than confidentiality, and is harder to do than is often thought. A lot of demographic information is available from private companies, so just

leaving a name off of the study records won't necessarily provide anonymity. Given just the parameters of a study, a subject could be identified. For example, Helen McGough explained that she can guarantee that there is only one 52 year-old, Hispanic, female, dental hygienist from Island County, WA who graduated from UW in 1985, and all of these questions could reasonably be asked in a study. Therefore, leaving off the name would not protect this person's anonymity, although it could still be confidential.

The Internal Review Board (IRB) at UW educates researchers on designing studies with anonymity and confidentiality in mind. The IRB establishes conditions to define "invasion of privacy" and "confidentiality agreements." Confidentiality agreements are also defined by Washington state law. There is up to a $10,000 fine if a confidentiality agreement is breached. There is also protection offered by the "Federal Certificate of Confidentiality."

Definitions have expanded in recent years. For example, "sensitive information" now includes information about health care and employment. Helen McGough explained that a good test to researchers about what is and is not "sensitive information" is, "Do you want to see this on '60 Minutes'"?

Yvonne Sherman asked if federal and state confidentiality agreements are always used in UW research. Helen McGough replied that the agreements are used only when information is truly sensitive and it isn't anonymous. There are, of course, some exceptions in confidentiality agreements. For example, if a researcher is indicted for wrong-doing, the data can be opened, although it can't be used to prosecute study subjects. Also, federal agencies can have access to the data in some cases. But, she stressed, confidentiality agreements can benefit researchers by establishing trust between the study subject and researchers.

Tim Takaro gave an explanation of the types of data he has been working with from health studies on former Hanford workers. He explained that access to medical information at the Department of Energy-Richland Operations Office (DOE-RL) has been relatively straightforward, but that other types of information have been more difficult to obtain, mostly because of bureaucratic difficulties.

Ruth Yarrow asked about the policies on genetic studies, both at UW and in the scientific community in general. Helen McGough replied that good science minimizes the risk of discrimination, while gaining more information about biomarkers or susceptibility. She gave an example about "pedigree" or family research. To do this type of study, researchers take a biological sample of some type and then lay out a family pedigree to look for possible genetic components. In order to have an accurate pedigree, researchers need to be sure that people really are related to who they say they are related to and so paternity tests are performed. In the United States, up to ten percent of the population's paternity is misassigned, so subjects need to be informed that paternity testing is being done, and that they may receive surprising news.

In situations like these, loss of confidentiality can cause external stigmatization, anger, guilt, and relationship problems, even if the subject never develops the disease. There are also testing issues in regards to genetic research. Do you test all of the children in a family, or only those who want to be? Communal stigmatization can also occur. Some communities have a high rate of genetic birth defects, or cancer, and if a person tests positively for the genes, their relationships within the community can suffer. Genetic testing can also be used

by those with racist agendas to backup their beliefs.

Helen McGough ended her presentation by stressing that genetic testing, as well as health studies have tremendous benefits, but that risks to the subjects need to be carefully weighed.

Introduction and Meeting Business

Openness Advisory Panel (OAP) Update

Since Max Power, who represented HOW at the February 13 OAP meeting in Richland was not in attendance, Michael Kern gave an overview of that OAP meeting and asked workshop participants if they had anything to add. Greg deBruler contributed several comments at the OAP meeting including a request for a cross-site Freedom of Information Act (FOIA) request tracking system. He added that openness is really for Department of Energy (DOE) managers, and there is a need for hard-core managers. He explained that the problem isn't money but attitude. He also added that OAP needs more of a perspective from the sites and that there is need for transparency throughout DOE.

Rick Stutheit was also at the OAP meeting and he added that Max Power's presentation was excellent. He explained that the OAP does see declassification as only a part of openness, just as the participants of the Hanford Openness Workshops (HOW) do.

Yvonne Sherman added that her experience with upper level management at DOE-RL is that they are very supportive of openness efforts. She said that they don't always understand the process, but give lots of philosophical support. Also, she added that records management is another large issue to deal with and that large amounts of money can be involved.

Tim Takaro asked about DOE-RL contractor participation at the OAP meeting. Yvonne Sherman replied that none of the contractors were really invited to participate, but it was an open meeting, so people did come by. She added that there was a SPIRE computer program demonstration by Pacific Northwest National Laboratories (PNNL) personnel as well as a site tour and some other presentations by contractors. Tim Takaro asked if Fluor Daniels was involved and Yvonne Sherman replied that some of the records management staff were there as technological issues and resources were discussed. She explained that it was an OAP business meeting, so OAP set the agenda.

Adoption of Working Group Reports

The remainder of the workshop focused on finalizing the text and recommendations for the Hanford Openness Workshop Report, to be available in summer 1998. Participants discussed the report section-by-section.

Section II. Introduction: An Overview of the Hanford Openness Workshops

There was a discussion about the wording of types of information in the Introduction section. Yvonne Sherman and Mary Lou Blazek will work on drafting wording about "legally available" information accessibility.

Greg deBruler pointed out that there is no mention in the Introduction of the struggle involved in getting to the point of having the Workshops. Mary Lou Blazek agreed. She and

Greg deBruler will work on a paragraph to this effect for this section.

There was also a discussion about the lack of the words "transparency" and "transparent" in the report. Elaine Faustman agreed with others that the term "open and transparent decision making" should replace "open decision making" throughout the report.

Section III. A History of Openness at DOE

Michael Kern explained that appendices were not included with this draft because they are items that participants should have seen several times, and it was decided not to waste the paper copying them all again. All appendices will be included in the next draft of the report. Dirk Dunning expressed a concern over the number of acronyms in the report. Michael Kern suggested that acronyms be spelled out as they are used at the beginning of each section, not just at the beginning of the document.

Roger Heusser wondered if this history should mention major breakthroughs in declassification, like the release of the Green Run report. Mary Lou Blazek agreed that it was a high point in declassification efforts, but thought that we would need to explain too much about what the Green Run was for it to be a good example. Tim Takaro said from a public health standpoint, the Green Run was a clear case of a study without informed subjects and very much a health risk. Greg deBruler thought that it would be possible to add a few sentences about the Green Run because the example shows what increased public pressure can do to facilitate information release. Norma Jean Germond felt that since the Green Run wasn't even the largest intentional release from Hanford, maybe there would be an even better example. Mary Lou Blazek suggested that Tim Takaro write up a sentence on the Green Run to include in the report and other participants agreed.

Dirk Dunning said that several elements being discussed pertain to work that the Hanford Environmental Dose Reconstruction (HEDR) project and other studies are dealing with, especially in regards to historical policies and decisions. He asked the participants if they knew when the word "openness" first came into use. Tom Carpenter and Greg deBruler had differing dates for the first mention of "openness" and Dirk Dunning felt that this proved his point exactly. Depending on the definition of "openness," the use of the word and the concepts behind it differ.

Greg deBruler asked that the report be consistent in abbreviating the Richland Operations Office "DOE-RL." He will email citations for his section of the report to Tiffany Potter-Chiles and Michael Kern.

Tim Takaro asked to add wording about impeding access to information in to the last paragraph in Section III. Michael Kern asked if this narrows the focus, and Tim Takaro explained that he doesn't want to narrow the focus, but to focus on specific problems. Dirk Dunning added that information access is not just a command down process, but that without DOE Headquarters (HQ), this work wouldn't happen, and that without public pressure it wouldn't happen either. Greg deBruler and Mary Lou Blazek will fix the wording of this section based on Tim Takaro's request.

Doug Huston had several grammar corrections to the report. Tom Carpenter will write a section on former Secretary Hazel O'Leary's statements about openness for this section.

Section V. Creating an Open Environment for Hanford Employees.

(Participants postponed discussion of *Section IV. Using Performance Measures to Promote Openness* until later in the meeting.)

Dirk Dunning commented that regarding the K-Basins at Hanford, there are problems with decision-making detriments, in general, not just employee retribution incidents.

Tim Takaro asked about incidents regarding exposures to workers. He said that public health information is available and would like to add something about that to the section. He will work with Dirk Dunning and Tom Carpenter on this.

Elaine Faustman asked to rearrange the bullets in the second paragraph of the section in chronological order. Tom Carpenter asked what had happened to the recommendations in this section and Michael Kern explained that all recommendations had been moved to *Section IX. Recommendations,* at the end of the report. Ruth Yarrow would like to have the executive summary linked to the recommendations section, in case readers don't want to wade through the entire report. Participants agreed and Michael Kern suggested having one to three key recommendations from each section listed in the executive summary, with reference to the full recommendations section. Participants agreed.

Section VII. Using Information Technologies to Improve Access and Openness

Dirk Dunning thought that it would be helpful to have more information on technologies in this section, like the SPIRE demonstrations. Tom Carpenter added that it would be useful to explain how information retrieval-type technologies are enhancing openness. Norma Jean Germond said that it needs to be explained that the technologies are not yet perfect, but under development. Michael Kern suggested that Yvonne Sherman, Tom Carpenter, Dirk Dunning, and Greg deBruler work together to draft a section adding these elements. Michael Kern also stressed to participants that as we are closer to printing, if comments are not received in a timely manner, they won't be included in the final report.

Tim Takaro asked to include wording about problems and limitations in the general field of information systems and public presentation systems. Michael Kern suggested that this may be an unaddressed/continuing issue, as it was not really discussed over the course of the four workshops. There was also a discussion about input from all participants into the report, even if they had not been a part of a particular working group. Tim Takaro felt that the report will be richer with more input.

Section VIII. A Tribal Perspective on Openness

Nanci Peters from the Yakama Indian Nation participated in the workshop on behalf of Russell Jim. Angel McCormack from the Nez Perce Tribe participated in the workshop for the first time and commented that she had not yet read the draft report. Michael Kern explained the background of the "Tribal Perspective on Openness" section. Elaine Faustman commented that it is important to have further explanation in the section regarding the government to government relationship between Tribal governments and the federal government.

Roger Heusser suggested that the recommendations section be tied back to these sections.

He also suggested citing more specific examples in the section, so that readers not familiar with Northwest Native American concerns can understand the issues. Nanci Peters suggested citing work done by the Columbia River Comprehensive Impact Assessment (CRCIA) and Barbara Harper and Stuart Harris's Native American Subsistence Scenario (NASS). Michael Kern suggested that CRESP work with Nanci Peters, Russell Jim, and Angel McCormack on incorporating language used in "Risk Roundtable: Evaluating Risk from a Tribal Perspective" materials to add more specifics to this section

Public Comment:

Roger Heusser from the DOE-HQ Office of Declassification presented current statistics on declassification efforts (see Attachment #1). He explained that the trend is reversing: the number of declassified existing documents has gone down while the number of newly classified documents went up. Workshop participants expressed their concern by this trend.

Adoption of Working Group Reports, cont.

Section IV. Performance Measures for Openness

Gerry Pollet told workshop participants that a new contract was signed by DOE-RL on 11/23/97 by DOE-RL staff and contractors but that it was not publicly available for a time. He also expressed his disappointment that the contract did not include any of recommendations forwarded by workshop participants in their 11/14/97 letter to Secretary Peña. Gerry Pollet suggested highlighting this in the report. He also added that 1999 performance measures are currently being negotiated.

Gerry Pollet said that he would like to see more detail in the Recommendations section. He would like DOE-RL and DOE-HQ recommendations differentiated from each other. He added however that the performance measures criteria could be applied site-wide. Michael Kern suggested deleting the bar on the table for those recommendations that apply to both DOE-RL and DOE-HQ.

Mary Lou Blazek is also disappointed about DOE-RL not incorporating participants' suggestions into the performance measures of the contracts. She asked participants if it would be most effective to repeat what they have already said, or if something else should be done. She said that based on the letters received in response to the letter to Secretary Peña DOE-HQ is interested in the suggestions, but that DOE-RL is not. It is important to state in the report that DOE-RL's response does not meet HOW participants' expectations.

Greg deBruler added that participants need rationale from DOE-RL for why their suggestions were not incorporated. Elaine Faustman said that CRESP hears from DOE-HQ that stakeholders get upset when their suggestions are not incorporated into DOE-HQ's work. But stakeholders are actually mostly upset that the system is not transparent. Gerry Pollet continued that to some at DOE, stakeholders participating in contractor evaluations is an alien idea. But, Fluor Daniel, for example, did include stakeholder input in their self-evaluation.

Michael Kern suggested that Spokesperson Mary Lou Blazek work with Gerry Pollet on language to express these ideas in the report, as well as a follow-up letter to DOE-HQ on DOE-RL's response to participants' suggestions.

Section X. Lessons Learned

Greg deBruler stated that most DOE employees don't know what "openness" is. He suggested adding another bullet in the "Lessons Learned" section about openness policy awareness. He thought that it was important that DOE employees know what their own policies say. Without this, he doesn't think that there is a reference point from which to hold management accountable.

Mary Lou Blazek asked about the best way to bridge the gap between stakeholders saying "you aren't doing what you said you would" and DOE management saying "yes we are." She didn't think that writing another letter will do it. Elaine Faustman suggested adding language in the "Lessons Learned" section saying that DOE management will be "aware and adhere to" their policies, but Mary Lou Blazek thought that all DOE management will say is "We already are." Greg deBruler suggested asking for the rationale behind DOE-RL's not using recommendations, and if they object, then cite policy. Tom Carpenter gave an example of when DOE contractors asked for whistleblower training. He said that DOE tells contractors they're going to be held accountable, but DOE doesn't hold itself accountable. He wondered if participants have any other avenue besides letters to express their dissatisfaction. Tim Takaro suggested a forum in John Wagoner's office to address some of these issues. He thought that at the least, it would get everyone on the same page, because he agrees that letters aren't doing it.

Michael Kern suggested that this discussion could continue during the discussion of the distribution and dissemination of the report. Doug Huston suggested an evaluation of follow-up to the report with John Wagoner. Michael Kern pointed out that in the HOW charter, DOE-RL is required to respond, "in writing and with direct dialogue" to HOW recommendations.

Mary Lou Blazek asked about the budget proposal for the 1999 Hanford Openness Workshops. She wanted to know if participants would like to propose becoming a "panel" or if they would like to stay a "workshop". Ruth Yarrow asked her to define "panel." Mary Lou Blazek explained that "panel" has an official federal definition and that includes being in an advisory capacity with a charter based on the Federal Advisory Committee Act (FACA). Greg deBruler suggested that "panel" has a connotation that the group is on-going and permanent. He thought that it would be possible to call it something else, but to still have that connotation. Mary Lou Blazek agreed that she didn't care what the group is called, but she would like to have the permanence and clout of a "panel."

Michael Kern asked if calling the group a "panel" vs. a "workshop" would affect the likelihood of receiving continuing funding, and asked whether a change of name from the Hanford Openness Workshops to the Hanford Openness Panel might be confusing at this point. Yvonne Sherman said she didn't think it would affect funding. She also asked if it would be possible to attach the Hanford Openness Workshops to the Hanford Advisory Board (HAB), as they are currently reorganizing. Greg deBruler said being attached to the HAB would mean also being attached to HAB funding. This could be a problem, as some people on the HAB don't see the value of the workshops. Dirk Dunning added that the HAB feels like they're taking on too many issues as it is. Greg deBruler asked about the possibility of attaching the group to the Secretary of Energy's Advisory Board-Openness Advisory Panel (SEAB-OAP). Ron Skinnarland, who participated in the workshop on behalf of Max Power, commented that he thought the group needed some sort of national

attachment; maybe "workshops" are a fallback position, but they should shoot for a "panel."

Michael Kern suggested writing a recommendation about exploring an affiliation with the OAP. Yvonne Sherman said that a few years ago, when this issue was first discussed, the OAP said that they didn't have any money to fund a site-specific group. They also suggested that the group not add a headquarters level of bureaucracy, but to just focus on the site-level. Ron Skinnarland said that he understood the concern for permanence but even without FACA-based charters, etc., as long as there is a need, there will be permanence. Michael Kern added that "affiliation" can mean many things. Being affiliated with the OAP doesn't have to mean becoming a physical part of that entity. It could mean communicating regularly, sending liaisons to each other's meetings, supporting each other's work, etc.

Greg deBruler felt that the group should try to get funding as a panel He thought that Tom Cotton and others from the OAP were very interested in the having the group funded. Mary Lou Blazek added that the final budget is being prepared so participants will have an idea of how much it costs to fund a group like this. Greg deBruler asked that the budget show figures for in-kind donations of time. Michael Kern said that the report would include a budget and scope of work of FY 1999 and title them "Hanford Openness Panel."

Tom Carpenter suggested spending the first meeting of the Hanford Openness "Panel" reviewing DOE's response to the report, or possibly adding a meeting to the proposal to fit this topic in. Greg deBruler added that the goal is to change DOE-RL culture, so the panel will at some point need to interface with management. Ruth Yarrow thought that the final meeting might be a good time for management to come in to respond and interact with participants. Yvonne Sherman agreed that this is a good idea, but also thought that DOE-RL management should have a "heads-up" about getting a "report card," as the draft 1999 scope of work proposes.

XII. Fact Sheets

Michael Kern pointed out that all of the fact sheets will be reformatted to match the report layout (and content where appropriate).

Tom Carpenter added that there are a lot of independent groups that could be mentioned in the fact sheet listing DOE-related World Wide Web addresses (URLs). He suggested taking a look at the Hanford Homepage. Dirk Dunning also suggested classifying the URLs into broad categories for easier reference.

Tim Takaro suggested adding another fact sheet on privacy act issues. Yvonne Sherman added that another group is writing one and suggested that the HOW distribute that one instead. Tim Takaro thought that there should be reference to other information access barriers.

Yvonne Sherman asked participants who the intended audience is for the fact sheets. Mary Lou Blazek responded that it is the general lay public, and should probably include the Tri-Party Agreement (TPA) mailing list, as well as be distributed at HAB meetings, over the web and to DOE Reading Rooms. Yvonne Sherman asked to have the web address of the Hanford Openness Workshops homepage on the fact sheets. Michael Kern added that the mailing address and phone should also be included.

Elaine Faustman asked about the fact sheet on categories of classified information. She wondered if it would be possible to give readers some indication of where information like this might be found. She asked if there is a way to make the fact sheet more useful. Doug Huston thought that this might not all fit in a fact sheet. Gerry Pollet agreed that if the public comes in and asks for a certain type of information, it would be helpful to be able to tell them where to start looking. Elaine Faustman suggested a Frequently Asked Questions (FAQ) fact sheet. Mary Lou Blazek said that she has had difficulty explaining to the public how difficult it is to declassify, both the "how"s and "why"s. She thought that there is a need for this type of fact sheet, but maybe it should be done next year, until there is more time to prepare it and combine it with more information. Elaine Faustman thought that what we have could be included, but follow-up next year.

Dirk Dunning asked if the group can assume it will exist next year. He also asked if it would be possible to tally up the questions received by the HOW web page. Yvonne Sherman said that there have been no questions so far this year. Mary Lou Blazek had some concerns about the fact sheet by Rebecca Pixler and Tim Ewers, and would like have more work done on it before it gets distributed.

IX. Unaddressed/Continuing Issues

Rick Stutheit thought there should be a short comment in the executive summary about the benefits of the Openness Workshops, or maybe this could be included in the cover letter. Mary Lou Blazek agreed that there is another opportunity to state the HOW's case in the cover letter. Ruth Yarrow thought that a clear case could be made for why DOE-RL should want to continue funding the group. Tim Takaro added that the argument needs to be quantitative about benefits.

Michael Kern asked participants if they felt comfortable with CRESP drafting the executive summary, and CRESP and Mary Lou Blazek working on the cover letter. Yvonne Sherman wanted to know what was going to grab management's attention. Michael Kern asked if the "Unaddressed Issues" section should be placed somewhere else. Tom Carpenter suggested making the section into a text paragraph. Tim Takaro asked about calling the section "Unresolved Issues" or "Next Steps." The group chose "Next Steps." Tim Takaro also thought that it would make sense to have the "Next Steps" section in the conclusion.

Mary Lou Blazek thought that the "Lessons Learned" section should be rearranged. The last one should come first, for example. Ruth Yarrow agreed.

Norma Jean Germond asked about #7 in the "Unaddressed Issues" section concerning the National Dialogue. Michael Kern agreed that while this issue is not discussed in the report, maybe the participants would like to write a letter or have some other form of communication with DOE about this issue. Tim Takaro added that the National Dialogue is a real-life openness scenario and should be addressed. Yvonne Sherman pointed out that "National Dialogue" in this case should be spelled with a capital "N" and capital "D". Michael Kern asked participants if the handout from Ruth Yarrow (Attachment #2) addressed the concerns. Ruth Yarrow will draft text to include with the "Next Steps" section on this issue.

IX. Recommendations

Dirk Dunning asked if the recommendations would be better organized as text or a table. Michael Kern explained that several formats were experimented with and that the table was the most clear.

The rest of the discussion concerned edits to the recommendations section. Participants also discussed distribution and presentation of the report. Ideas included: HAB, Oregon Hanford Waste Board, DOE managers, site management decision boards, the Governor's Association and a congressional briefing. Participants would like to have a mixture of both local and national distribution. Other possibilities discussed included: press releases, presentations to other meetings, and other existing mailing lists. Michael Kern asked participants to come up with a "wish list" of distribution avenues and to remember that the report will also be available on the web.

The final draft of the report will include a dissemination plan and will be distributed by CRESP by the 1st week of June. Participants comments should be to CRESP by June 22nd in order to be incorporated into the final report. The report will be sent to the printers by the 2nd week of July.

Public Comment:

No members of the public made comments.

Meeting adjourned.

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For questions or comments about this page, please send email to Yvonne_T_Sherman@rl.gov
URL: http://www.hanford.gov/boards/openness/summary/051898.html
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